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AUTHOR	Fesko, Sheila; Freedman, Ruth
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ABSTRACT

This qualitative study examined the perspectives of people with significant disabilities (N=23) and their family members about their overall employment experiences, outcomes, and expectations. Four focus groups were convened, two groups of people with significant disabilities and two groups of family members. Disabilities represented included mental retardation, physical and psychiatric disabilities, sensory impairments, and substance abuse. Key topics discussed in both consumer and family member focus groups included: (1) job outcomes/satisfaction (both groups indicated feeling productive and keeping busy were essential aspects of work); (2) obstacles to employment (disclosure of disability status, lack of appropriate services by state vocational rehabilitation agencies, and lack of appropriate job matches); (3) support at work (supportive role of job coaches and employers); (4) relationships at work (importance of feeling important); (5) goals and expectations (dead end jobs and plans to upgrade skills); and (6) family concerns (conflicts between encouraging independence and wanting to protect from harm). Implications for professionals working with individuals with disabilities include recognizing the importance of meaningful work in the lives of people with disabilities; addressing discrimination and stigma in the workplace; providing a variety of individualized supports on the job; and encouraging consumer and family involvement in the vocational rehabilitation system. (DB)

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Research → Practice

Institute for Community Inclusion
• The University Affiliated Program at Children's Hospital & the University of Massachusetts at Boston
• The Center on Promoting Employment (RRTC)

Consumer and Family Perspectives on the Meaning of Work

By Ron Lehmann and Sheila Fesko

August 1995

Introduction

This study reports the findings of a qualitative research study which obtained the perspectives of people with significant disabilities and their family members about their overall employment experiences, outcomes, and expectations.

Four focus groups were convened —two groups consisting of people with significant disabilities and two groups consisting of parents or spouses of people with disabilities—to discuss employment experiences and concerns.

Participants

In the four groups, a total of 23 individuals with disabilities were represented. Family members' discussion was based on their perceptions of their family member with a disability. The types of disabilities of people in the consumer group or represented in the family focus groups included: mental retardation, physical and psychiatric disabilities, sensory impairments and substance abuse.

The types of jobs performed by consumers represented in the focus groups included: surveyor, child care aide, food service worker, secretary, mechanic, tele-sales, retail, computer programmer, driver/delivery, janitor, microfilm technician, office assistant, and assembler. Salaries of these consumers ranged from $4.24 to $17.00 per hour, with a median salary of $7.08 per hour. Consumers worked an average of 28 hours per week, and had been on their job for an average of 2.68 years. The length of time employed ranged from two months to eight years.

Key Topics

Job Outcomes/Satisfaction

Both consumers and family members indicated that feeling productive and keeping busy were essential aspects of work. This involved doing meaningful work, having a routine and structure, assuming responsibility, doing a variety of tasks, and completing work on time.

Self-esteem and well-being of individuals was also rated by both consumers and family members as critical to job outcome.

"Just knowing that you have the ability and can do it, and being given the chance to do that."

For consumers, compensation and benefits were important job outcomes.

Parents and spouses felt that opportunities to interact and socialize at work with customers, co-workers, and employers contributed heavily to their family members' feelings of job satisfaction and importance. Opportunities for socialization were not cited as an important job outcome in the consumer focus groups.

Obstacles

Consumers stated that they faced problems in getting or keeping jobs due to the stigma surrounding their disabilities and discrimination on the part of the public, including employers and professionals. Disclosure of disability status was a key concern.

The second major barrier to employment expressed by consumers was the lack of available, appropriate services by state vocational rehabilitation agencies, including a lack of staff follow-through.

Family members cited lack of appropriate job matches as a major barrier for their relatives with disabilities. Placements were made in jobs because there were openings, not because consumers were interested in or had aptitude for that type of work. Lack of transportation was frequently cited by family members, since many relatives with disabilities depended upon public transportation to get to work and were therefore limited in their job search to worksites accessible by bus or subways.

Support at Work

Both consumers and family members identified professional staff as critical sources of support at work. Many consumers felt that these staff people provided a feeling of security and reinforcement on the job.

Some families expressed concerns about the time limited nature of job coaching, and were anxious about problems that could arise when a job coach was no longer available.

Consumers also frequently cited the important supportive roles assumed by some employers.

"They (the employer) gave me the encouragement. They didn't let me sit back and feel there was nothing I couldn't do...And from the experience, I found that it helped me branch out."

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Relationships at Work

Many consumers expressed their feelings of belonging or acceptance at work. Praise received from customers and employers made some consumers feel that they were valued and accepted.

One consumer stated:

> *"It's very friendly where I work, but I've never made many friends. I have people I like and get along with, but no real friends."*

While most consumers did feel accepted in the workplace, a small number of consumers mentioned co-workers who were uncomfortable with or patronizing toward them.

Goals and Expectations

Many consumers were content with their jobs and expected that they would remain in their current positions. Others discussed plans to upgrade their skills and seek better jobs.

Consumers and family members expressed concern about "dead-end" jobs and the desire to upgrade to jobs that were more appropriate to their skills and interests. Some consumers expressed frustration with these jobs, but had plans to develop their skills and move on to more challenging opportunities. Others acknowledged that while they felt they were capable of more challenging work, they regarded their current job as an appropriate and necessary step for them at this time.

Family members, on the other hand, tended to see consumers as having limited potential for advancement from these jobs and envisioned that their family members would need to remain in these jobs long term.

Family Concerns

Parents expressed the conflict between wanting to encourage the independence and self-sufficiency of their adult children, yet at the same time, wanting to protect them from possible harm.

Strongly related to conflicting feelings about "letting go" were parental concern about the future. As one parent expressed,

> *"What's going to happen when we're not around? Is he going to be able to take care of himself?"*

Family members expressed concern about the importance of maintaining the dignity and self-respect of their relatives with disabilities. Many parents and spouses were concerned about the negative impact of the disability "label" on their relative. In general, family members felt that the label of having a disability limited their relatives' options, and that staff and the general public were too negative in their expectations for their relatives. This concern is consistent with the consumers' concerns regarding stigma and job discrimination discussed earlier.

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Family members felt that they played a vital "full-time" role in the lives of their relatives with disabilities, helping them find employment, explore job opportunities and resources, and keep up their morale. Family members felt that these responsibilities had an impact on overall family functioning.

Overall, family members expressed a need for support and understanding by the community. As one parent said,

> *"The family is in a cocoon and you're looking out. No one is looking in or understands."*

Implications

Professionals working with individuals with disabilities need:

To understand the importance of meaningful work in the lives of people with disabilities

- Work plays an integral role in developing self-esteem as well as a sense of being part of society
- Work needs to be consistent with the individuals goals and interest, not just compatible with available job openings

To address discrimination and stigma in the workplace

- Importance of educating employers concerning issues for people with disabilities
- Education of consumers concerning their employment rights under ADA
- Need for counselors to work with consumers on individualized strategies to deal with disclosure issues

A variety of individualized supports and opportunities on the job

- Use of natural supports of co-workers and supervisors on job site
- Flexible job coach support that responds to individual and family needs

Greater consumer and family involvement in the vocational rehabilitation system

- Education of consumers as to their rights and responsibilities in the VR system
- Empowerment of consumers to take control over their decisions
- As appropriate, active family involvement of family in rehabilitation system through support and information sharing

The Center for Promoting Employment: RRTC is a project of the Institute for Community Inclusion and Boston University Center on Work and Family. For further information on this study, please contact: Sheila Fesko, Institute for Community Inclusion, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115 (617)355-6506 voice; (617)355-6956 TDD